

# Implementation guide and resource pack for dementia care



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- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in, access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

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# 1. Aims of this document

**1.1** This guide aims to set out the policy drivers and strategic context for transforming dementia care, and why it is of importance to commissioners, providers and sustainability and transformation partnerships (STPs) in supporting delivery of a number of objectives in the Department of Health's [Prime Minister's challenge on dementia 2020](#), published February 2015, which complements the aims of the [Five Year Forward View](#), published in October 2014.

**1.2** It provides local services with evidence on what works in dementia care, headline access and quality benchmarks to support a reduction in unwarranted variation and draws on a number of good practice case studies throughout. Its overarching aim is to ensure that people with dementia, and their carers, receive good care and support; that no one has to wait months for an assessment of dementia.

**1.3** This guide is important, not only for the NHS but for people with dementia and their carers too. It demonstrates our commitment to improving the quality of dementia care across the whole country, building on improvements to date and ensuring that we can provide excellent care and support for those who need it.

**1.4** The NHS has finite resources so it benefits us all to think of new and innovative ways to design services, to ensure that high standards of care can be delivered in cost efficient, sustainable ways. By doing this we can improve outcomes, in the case of dementia this often means improving the quality of someone's life, and their carer's, and reducing their reliance on the health care system. This has a benefit to the wider system as resources can be redeployed and those living with dementia can continue to live independently for longer and enjoy being part of their community.

**1.5** Commissioners, service managers, clinicians, people with dementia and carers directly involved

in designing and delivering local dementia care pathways should read this guide. This has been produced by the National Collaborating Centre for Mental Health (NCCMH) in conjunction with the National Institute for Health and Care Excellence (NICE) and NHS England.

**1.6** This guidance was co-produced by a national expert reference group (ERG) comprising experts by experience, clinicians, service managers, commissioners, academics, people with dementia, carers and others. Local service design should be similarly co-produced to meet the needs of the local population.

**1.7** All clinical pathways should be tailored to people's personal circumstances, considering **culturally specific beliefs, needs and values, as well as supporting carers and families of people** with dementia.

## Case studies: Involving service users and carers in service design:

- [Newcastle Memory Assessment & Management Service](#)
- [Gellwood House memory service](#), Carlisle

"Involving people with dementia and carers in developing dementia services can often be a tick-box exercise with no real meaning. I am fortunate as I live in an area that puts me and my wife and people like us at the centre of everything that concerns dementia. ... in fact, I am busier now than when I was working!

Doing 'with' rather than doing 'to' is vitally important to ensure services are developed that people with dementia and their families not only want and need, but deserve and expect."

Source: **Dr Trevor Jarvis**, Dementia Ambassador and person living with dementia.

## 2. Policy and strategic context for transforming dementia care

**2.1** The Five Year Forward View and the Department of Health's Prime Minister's Challenge on Dementia 2020 highlight the importance of good dementia care. Dementia is a progressive, non-curable disease that affects around 670,000 people in England alone. It costs society an estimated £26 billion each year<sup>1</sup>. An estimated 25% of hospital beds are occupied by people with dementia<sup>2</sup> and their hospital stays tend to be on average one week longer. Further, approximately 75% of people living in care homes have dementia. It is also the leading cause of death.

**2.2** These reports set out a clear rationale for providing a consistent standard of support for people with dementia and their carers. The [Next Steps on the NHS Five Year Forward View](#) report reiterates our commitment to diagnosis and post-diagnostic support for people with dementia and their carers so that people can live independently in their own homes for longer, preventing crises and avoiding unnecessary admissions to hospital.

**2.3** The Department of Health [Implementation Plan](#) for the 2020 Challenge on Dementia sets out a roadmap for improving dementia care by 2020 in line with the aspiration for England to be recognised as the best country in the world for dementia care and support. The priorities for service improvement set out in this document directly support these aims.

### What is dementia care?

**2.4** Dementia care encompasses the five elements of the [well-pathway for dementia](#); preventing well, diagnosing well, supporting well, living well, and dying well. Our priorities, as set out in the [Next Steps on the NHS Five Year Forward View](#) report, are to maintain a focus on diagnosis and post-diagnostic support.

**2.5** Whilst dementia is most prevalent in older adults, good dementia care includes adults of all ages. It also includes carers of all ages.

**2.6** Further information and resources about dementia services can be found on the NHS England dementia [resources](#) internet page and in case studies provided throughout this document.

### Key statements: what does good dementia care look like?

**2.7** The statements<sup>3</sup> on the following page, developed by the national expert reference group, are based on the perspectives of people with experience of receiving and providing dementia care and underpin the importance of developing dementia care with the person at the centre.

<sup>1</sup>Dementia 2014: Opportunity for Change, Alzheimer's Society, September 2014.

<sup>2</sup>Counting the Cost – Caring for people with dementia on hospital wards, Alzheimer's Society 2009

<sup>3</sup>Alzheimer's Society have recently published refreshed 'we' statements to replace the 'I' statements (Not adopted here)

Key statements	
“I was diagnosed in a timely way”	We know that if I am referred for an assessment for dementia, I will receive a timely diagnosis and agree on an initial care plan.
“I am able to make decisions, and I know what to do to help myself and who else can help”	<p>We know that I will have a personal choice in decisions affecting my care and support.</p> <p>We know that I will be able to jointly develop my care plan.</p> <p>We know that if I need help, I will be supported to make a decision, for example through the use of independent advocacy services.</p>
“I am treated with dignity and respect”	<p>We know that services are designed around us and our needs, and that they will be appropriately staffed and staff will have the right levels of training.</p> <p>We know that services will provide the best possible care, and will be regularly reviewed by other agencies.</p>
“I get treatment and support which are best for my dementia and my life”	Once I am diagnosed, we know that we will have a named coordinator of care who will jointly review my care plan with us as our needs change. This will happen at least once a year.
“Those around me and looking after me are supported”	<p>We know that my care plan will cover my own needs as well as those of the people who support me. This will include our emotional, psychological and social needs.</p> <p>We know that a carer’s assessment will be offered.</p>
“I feel included as part of society”	We know that my care plan will give us the support we need to live well. This may include helping me build relationships, be involved in my community or engage in activities that I enjoy.
“I am confident my end-of-life wishes will be respected and I can expect a good death”	We know that my care plan will help us to plan for the future, including my end-of-life wishes.

## 3. Access and quality benchmarks for the dementia care pathway

**3.1** The NHS Mandate 2017-2018 states that we should make measurable improvements in the quality of care and support for people with dementia in line with progress towards the Challenge on Dementia 2020 Implementation Plan.

**3.2** [NHS Operational Planning and Contracting Guidance](#) 2017-18 sets an expectation in providing dementia care to:

- increase the number of people being diagnosed with dementia, and starting treatment, within six weeks from referral; and
- improve the quality of post-diagnostic treatment and support for people with dementia and their carers.

### Evidence

**3.3** Data from the [Second English National Memory Clinics Audit Report](#), published December 2015, told us that the average waiting time from referral to assessment was 5.4 weeks, with a further 8.6 weeks between that assessment and receiving a diagnosis, but with significant variation between clinics.

**3.4** Access to NICE recommended treatment is also variable. We know from Quality Outcomes Framework (QOF) data that 77% of patients in primary care with a recorded diagnosis of dementia received a face to face care plan review in the previous 12 months<sup>4</sup>, but this does not record whether their care plan was of high quality.

**3.5** It is clear from this evidence that although some services are providing a good level of care with regards to waiting times, there is still unwarranted variation in the system which needs to be addressed. Further, the adoption of a high-quality care plan is essential if we are to support people with dementia and their carers appropriately.

**3.6** A recently published [dementia RightCare scenario](#) illustrated the potential cost savings that be generated from the adoption of an optimal care pathway. In this example, an optimal care pathway almost halved the costs of dementia care over a ten year period.

### What constitutes NICE recommended dementia care?

**3.7** Priority areas identified for quality improvement by NICE are set out in the [Support in Health and Social Care](#) and [Independence and wellbeing](#) quality standards for dementia care. These state that:

- People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.
- People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local areas.
- People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.
- People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care, that identifies a named coordinator of care and addresses their individual needs.
- People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.
- People with dementia receive care from staff appropriately trained in dementia care.

<sup>4</sup>2015/16 QOF data

### Diagnosis

**3.8** Primary care services are typically the first point of contact for a person, family member or carer who suspects dementia. Key roles within primary care involve:

- carrying out an initial assessment and preliminary investigations in people with suspected dementia; and
- referring on to memory assessment services for a diagnosis and assessment if appropriate and with the person's consent.

#### Case studies: How services can be configured to provide an optimal pathway:

- [Enfield memory service](#)
- [Stockton memory service](#)
- [Hambleton and Richmondshire memory service](#)
- [Devon partnership project group](#)

**3.9** Key roles of memory assessment services include:

- reviewing and/or conducting preliminary investigations (including physical examinations and taking the person's history);
- arranging specialist investigations, including neuropsychological assessment and brain scans, where these are indicated;
- providing a diagnosis of dementia, including atypical presentations and mild cognitive impairment; and
- developing and initiating the care plan following diagnosis with the person and all relevant carers and providers of care.

**3.10** Memory assessment services may be configured in a range of ways, including:

- those provided by secondary mental health care providers, either as stand-alone memory clinics or services, or integrated with older adult community mental health services;
- cognitive neurology clinics or neurology services;
- clinics provided by geriatricians or old age medicine services through acute (medical) trusts;
- GP led clinics/services supported by specialist advice and assessment from one or more of the services above; or
- integrated services, with co-location and/or joint working between one or more of the providers above.

### Post-diagnostic support

**3.11** A core component of person-centred dementia care is the support of a **named coordinator of care** and the presence of a flexible, up-to-date care plan. This person should be allocated based on personal need, and may come from various settings, for example primary care, the voluntary sector or memory assessment services.

#### Named coordinator of care: key role

- **Facilitate choice, independence and person-centred care**, including, where appropriate, seeking informed decision-making and valid consent through use of advance directives and the [Mental Capacity Act 2005](#)
- **Signpost** people with dementia and their carers to local support services and to ensure continuity of care
- **Jointly develop and review the care plan** with the person and their carer, at least every 12 months, to ensure that it is still applicable and effective
- Ensure the person's **physical and mental health** is monitored and that they can access appropriate treatment



**3.12** A key theme of dementia care is to enable the person living with dementia and their carer to live meaningful and independent lives. The provision of support should be person-centred and holistic. This support may be provided via health and social care, local authorities or voluntary organisations.

“The openness and honesty of [a named coordinator of care] really helped me, followed by meeting some exceptional people who have worked with me over the past five and a half years have, made living with dementia almost bearable.”

**Source: A person living with dementia**

**Person-centred support may include:**

- **appropriate housing provision** such as extra care housing
- **support to maintain relationships** both at home and in the wider community
- **support to maintain independence**, including dementia-friendly communities, advocacy services, homecare services, campaign services and information provision
- **support to engage in meaningful daily activities**; this should be person-centred and may be provided on an individual or in group basis across a variety of settings
- **support, training and advice for carers, including respite care, peer support groups and training courses**; support may also be provided in the work environment
- **practical support** including transport.

**3.13** The impact of dementia affects not only the individual but also their friends, family and local community. It is estimated in England that over 540,000 people act as primary, unpaid carers for people with dementia. Often, carers provide a pivotal role in enabling a person to live well with dementia, but in doing so they may face considerable emotional and economic burden.

**3.14 Carers** should be provided with support to not only cope with their caring responsibilities, but also to enable them to have an independent life alongside caring.

“I built up a brick wall and tried to do it all myself, hiding behind a mask that everything was ok but it wasn’t. My Admiral Nurse skilfully and gently chipped bits away. I learnt to trust her and because of her actions I realised that if I wanted to be an effective carer, which I want to be, I’ve got to acknowledge that I have needs and I’ve got to do something about it and to ask for help.”

**Source: A carer for a person living with dementia from Dementia Action Alliance, [The Carers’ Call to Action](#)**

**3.15** To be able to deliver our vision of effective, high-quality dementia care we need the right **workforce**, with the right capacity and skill mix, in the right place at the right time. The Dementia Core Skills Education and Training Framework sets out the essential skills and knowledge necessary for all staff involved in dementia care. It sets out standards needed in dementia education and training including raising dementia awareness, knowledge and skills for those that have regular contact with people living with dementia and knowledge and skills for those in leadership.

### Case study:

- Dementia training at [London Ambulance Service](#)

## 4. How to deliver high-quality dementia care

**4.1** Whilst this document sets out the high-level expectations of dementia care commissioning, it is up to local areas to decide how best to reconfigure and update existing provision to meet these requirements.

**4.2** Commissioners should continue to engage actively in local system leadership. An improvement agenda should be jointly developed with key partners including healthcare providers, social care, local government, and the voluntary and independent sectors. At the heart of this agenda should be people living with dementia and their carers, as well as the triple aim of: (1) improving the health and wellbeing of the whole population; (2) better quality for all service users, through care redesign; and (3) better value for taxpayers in a system that is sustainable.

**4.3 Strategic planning:** A set of clear, outcome-focused, strategic priorities and investment plans should be developed that highlight the short-, medium- and long-term goals linked to achieving an optimal dementia care pathway. Plans and decisions for change should be based on evidential data, and co-produced with key partners (including social care), service users and the wider public.

**4.4 Assessing local need and demand:** Effective approaches to reducing differences in access, experience of care and clinical outcomes are built from the best available evidence on why and how such variations occur. Commissioners should develop a rich picture of the current and future needs of the local population.

**4.5 Building a case for change:**

Commissioners should work with providers and wider stakeholders to agree an objective or future service model. Proposed models should be driven by evidential data and best practice.

**4.6 Manage the local system:** Once future quality standards, performance and workforce requirements have been outlined, an options appraisal for service improvement, recruitment and workforce development will need to be considered jointly with providers. This should include assurance that providers have a plan to collect and use outcome measures routinely as specified.

### Case study: Reducing waiting times and improving the provision of post-diagnostic support

In 2010, **Stockport CCG** had a dementia diagnosis rate of **40%** whilst also facing a 60% increase in referrals to the memory assessment service. For those that did receive a diagnosis, there was poor post-diagnostic support, exacerbated by limited partnership working between primary and secondary care.

Recognising that the system needed to change, Stockport CCG entered into a shared care pathway agreement with Pennine Care NHS Foundation Trust. This shifted the management of stable patients into primary care, with support from the memory assessment service as needed, including a fast track referral back to secondary care in the event of a deterioration in their condition. A local enhanced service was implemented to develop an action plan for each practice, additional monitoring of patients (financial incentive), and additional resources in the form of four link nurses.

As a result, Stockport CCG's diagnosis rate is now **74.9%** (March 2017); waiting times have reduced, with **95%** of people receiving a diagnosis within 6 weeks of referral. Patients now receive two reviews each year and GPs are better aware of the post-diagnostic support offer. All practices receive bespoke training and there is better usage of secondary care capacity.

Stockport invested £250k in primary and secondary care to increase capacity in the memory service and support GPs in undertaking dementia monitoring reviews and attending training. £150K of this budget is recurrent monies for the memory service. Part of the other £100K is now included in a GP development scheme to encourage GPs to have a dementia review with their patients twice a year (one in addition to the normal annual QOF review). GPs receive £30 per review for this.

## 5. Data collection and outcome measurement

**5.1** We already have excellent data on dementia diagnoses from primary care. This allows us to monitor the diagnosis rate each month and tackle any unwarranted variation between geographies.

**5.2** NHS England has been working with NHS Digital to ensure that routine reports are made available, via the Mental Health Services Dataset, on dementia care in memory assessment services. This will provide information about the performance of dementia care providers, including data on referrals, assessments, NICE-recommended interventions, and discharge to primary care. Detailed technical guidance about data collection can be found on the NHS England dementia [resources](#) internet page.

**5.3** Clearly defined outcomes that are routinely collected are an essential part of measuring and monitoring the performance and the effectiveness of a service. The Expert Reference Group has recommended that three outcome tools should be used routinely in memory assessment services. These are:

- **Health of the Nation Outcome Scale-65 (HoNOS-65):** a 12-item scale measuring behaviour, impairment, symptoms and social functioning in older adults.
- **Friends and Family Test (FFT):** a single-item scale measuring service user experience.
- **New Models for Measuring Patient Experience Questionnaire:** a 20-item scale that measures service user experience.



This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request.

Please contact **0300 311 22 33** or email [\*\*england.contactus@nhs.net\*\*](mailto:england.contactus@nhs.net)